# Introduction to Autism Spectrum Disorder

# What is Autism Spectrum Disorder?

## Autism Spectrum Disorder

- Affects a person's behavior, social and communication skills
- Symptoms generally recognized between 12-24 months of age, although average age of diagnosis is age 4
- 5:1 ratio of males to females
- No known cause, some risk factors such as older parents, low birth weight. 10-15% linked to a specific genetic condition
- Symptoms can range from mild to severe

#### Prevalence of ASD

#### Center for Disease Control Monitoring

Year of monitoring	1 in X children
2000	1 in 150
2002	1 in 150
2004	1 in 125
2006	1 in 110
2008	1 in 88
2010	1 in 68

#### VT data

- 2013 AOE child count 1000 children with ASD receiving special education
- FY12 DAIL 327 or 12% of individuals with ASD receiving HCBS "waiver", % is increasing
- 2009 Medicaid claims for children under 18 1211
- Don't have good numbers for adults

## State spending on autism

 2011 report to the legislature reported that in CY 2009, VT spent \$61M on 1,384 children with autism under age 18 in Medicaid and Special Education

## Everyone is Unique!

- Each person, regardless of their diagnosis, is a unique individual with their own strengths, challenges, likes/dislikes, hopes and dreams
- The diagnosis doesn't define who they are
- The characteristics explained below describe a range of challenges that a person may have. Not all people with the autism spectrum disorders have the same difficulties. There is a wide range abilities in people with autism spectrum disorders

#### Characteristics of Autism

- Social challenges
- Communication challenges
- Sensory challenges
- Behavioral differences
- Co-occurring diagnoses

#### Social Challenges

- Limited initiation or response to social interaction
- Limitations in using and interpreting nonverbal language, gestures, facial expressions
- Limited eye contact
- Difficulty understanding social rules

#### Social Challenges, cont.

- Understanding thoughts, feelings, and desires of others
- Difficulty developing and maintaining relationships

#### **Communication Problems**

- Range of communication difficulties, from non-verbal to sophisticated, but unusual, speech.
- Range of ability to understand language
- Tone of speech may be unusual, monotone
- Literal (concrete) understanding of speech, difficulty with jokes, sarcasm

### Communication Problems, cont

- Echolalia may repeat last words heard without regard to meaning
- Longer time to process and respond
- Back and forth of conversation, taking partner's perspective

## Sensory Challenges

- Heightened sensitivity or decreased sensitivity to sensory input
- May affect vision, hearing, smell, taste, touch
- Fascination with lights or movement

#### **Behavioral Differences**

- Unusually intense or restricted interests
- Unusual repetitive behavior
- Unusual sensitivity to environmental stimuli
- Unusual fears
- Difficulty with transitions
- Need for sameness, routines
- Aggressive, disruptive or self-injurious behaviors

## Co-occurring diagnoses

- Seizures (20-35%)
- Intellectual disability(46%)
- Tourette's disorder (motor/phonic tics)
- Learning disabilities
- Mood disorder (bipolar or depression)
- Anxiety disorders

#### Supporting individuals with ASD

## Treatment and Support for ASD

- No one treatment works for all people with ASD
- Must be individualized to strengths, need, interests and desires of the person
- Intensive early intervention during preschool years has be shown to make a significant impact
- Very structured, consistent, systematic instruction by trained staff

## Treatment and Support for ASD

- No proven medical treatments
- Some medications help with behavioral symptoms

#### Types of services people may need

- Information and referral
- Personal care services
- Speech/language therapy, OT
- Psychiatric/counseling/behavioral therapy
- Vocational services
- Supported living options
- Case management
- Family support

#### Federal And State Funded Resources

- Medicaid
- SSI
- Children with Special Health Needs
- Personal Care Services
- Children's Integrated Services
- Integrated Family Services
- Developmental Disability Services
- Mental Health
- Vocational Rehabilitation

#### **Education resources**

- Local special education program
- Vermont Agency of Education

## Vermont's Response to Autism

- 2005 State hired Autism Specialists at AOE and DAIL
- 2006 Interagency White Paper on ASD written
- 2008 Report to the Legislature to Address Services for Individuals with ASD

## Recommendations from 2008 report to legislature

- Develop best practice guidelines
- Enhance screening and diagnosis
- Access to early intervention
- Coordination of services across AHS/AOE departments
- Access to information
- Training and workforce development
- Technical assistance and consultation
- Enhance educational services
- Enhance adult services
- Ensure availability of adequate funding for services, including private insurance coverage

## VT response, cont.

- 2008 Vermont Interagency Autism Plan developed, advisory committee set up
- 2010 Act 127 passed, insurance coverage for treatment services for children under age 6 with ASD
- 2010-2013 State Implementation Grant
- 2012- Act 158 passed, expanded insurance coverage for treatment services up to age 21

## Current status of autism plan

- Goal A Screening and diagnosis
  - VCHIP provided training to 89 of 103 primary care practices in developmental and autism screening
  - % of practices reporting conducting autism screening increased from 58% in 2009 to 90% in 2013
  - VT- ILEHP trained 45 clinicians in diagnosing ASD
  - Best Practice guidelines for diagnosis developed in 2009

## Goal B – intensive early intervention services for young children

- Grant funded training of 9 CIS and 12 EEE programs in EBP
- Significant gains made in EEE programs/more modest gains in CIS
- Insurance legislation passed in 2010 and 2012 requiring coverage for diagnosis and treatment of ASD
- CIS hired two autism consultants

## Insurance legislation

- Medicaid and private insurance required to provide coverage up to age 21
- Still in process of implementation
- Many services already covered, e.g. counseling, SLP, OT, psychiatry
- Primary service not previously covered is Applied Behavior Analysis services
- Challenges with sufficient providers and setting up payment mechanisms

### Goal C

 MOU between AOE and AHS regarding responsibilities for implementing the interagency plan

#### Goal D

- Information clearinghouse and support for families
- Vermont Family Network received grant to develop website and provide phone support for families
- Website is being visited 3313 times by 1219 unique visitors per six month period

## Goal E - Training

- AHS/AOE have sponsored numerous trainings in ASD to enhance the workforce skills and knowledge
- DAIL recently provided grant funds to designated agencies to begin training more professionals in ABA

## Goal F- enhancing education

- Autism consultant continues to provide technical assistance to schools
- Sponsoring trainings
- Incorporating efforts into all their other school improvement projects

#### Goal G – Adult services

- Goal is to expand opportunities in employment, community living and post-secondary education
- Post-secondary opportunities are expanding around the state
- VT Autism Transition guide developed
- Autism Plan advisory committee are focusing efforts on this goal this year

## Summary and Conclusion

- The number of people with diagnosis of ASD is increasing
- Increasing need for services
- VT has been working to implement it's plan to enhance statewide services
- Still more work to be done to ensure that services meet the unique needs of people with ASD across the lifespan

#### For more information

- http://www.ddas.vermont.gov/ddasprograms/programs-autism-default-page
- <a href="http://www.vermontfamilynetwork.org/i-need-help-with/developmental-disabilities/autism/">http://www.vermontfamilynetwork.org/i-need-help-with/developmental-disabilities/autism/</a>
- http://www.cdc.gov/ncbddd/autism/index.html